

IMMUNIZATION REGISTRY FOCUS GROUP STUDY

October 12, 1998

Non Hispanic white, Lower Education

Portland, Oregon

Moderator: Wendy Child

SECTION 1: GENERAL IMMUNIZATIONS AND HEALTH CARE

I. Prevention

Participants mentioned the following as diseases they are most concerned about:

- Cancer
- Asthma
- AIDS
- Hepatitis
- E. coli
- Meningitis
- Chicken pox

II. Immunization

A. *Reasons not to get vaccinated*

- Fear of side effects from vaccines
- Religious objections
- Affordability
- Language barriers that prevent parents from learning or understanding what is important and required about vaccinations

Comments included:

[The fine print] is scary. I'm going to first of all inflict pain on my child and then, they're going to maybe get polio.

They always warn you at the doctor's that there could be a little side effect. You can get fevers for a couple of days. It's kind of worrisome sometimes when you get the first set of shots...

You almost want to take your kid and run for your life out of the place.

My kids are immunized, but I can respect that other people have different feelings about it. I hope they don't send [their children] to my kids' school...I don't hear as much that they're afraid of the complications [as about] the fact they have religious reasons.

B. Reasons to get vaccinated

- To prevent diseases

Comments included:

I can't imagine why a parent wouldn't want to keep up on those things.

C. Ways parents are reminded of vaccine schedule

- Doctor's office schedules appointments to coincide with vaccinations that are due
- Doctor gives you a schedule
- Articles in parenting magazines, especially about vaccines that are not required (e.g., hepatitis)
- Reminders from school
- No reminders: You take responsibility to keep track of it yourself

Comments included:

I take it personally upon myself to be aware of what is required for my children.

We have Kaiser and they have started every time you take a child in, they give you a printout along with whatever else, of their shots and I did not pay any attention...I have my own record [too]. I make sure they mark on the little health record because that's what the school wants...

D. Methods of easier tracking

- If more doctors provided a printout at each visit like Kaiser does
- If doctors could fax information to schools instead of parents having to show the record card

SECTION 2: IMMUNIZATION REGISTRIES

I. Initial reactions to the idea of a registry

- Most of the participants voiced initial reactions that were strongly positive. A few people were concerned about taxpayer cost and potential invasion or privacy.

Comments included:

I want it.

I think it's great.

It's wonderful.

I can't believe they don't have anything like this already.

It would have been nice when I was going to school. I wouldn't have had to re-do some of [the information] because my mother lost some of my records.

I think it's a good idea because not everybody wants to keep records in a file of your child's immunizations and take it to the doctor every time...

My initial reaction was 'great' but what exactly does it involve to have this available to us?...I'm as concerned as anybody about my privacy also. They might want to know a lot of things.

Who can hack into it besides the health care provider and the state and find out things? Add things? Delete things?

Along with it, you're going to have to have the child's Social Security number, so there's another avenue there for people who want to do bad stuff.

- One participant thought she had heard of the registry and that she had signed a consent form for it when her child was born. No one else had heard of it. Participants wanted to know:

Is it federal or state government that would be paying for it?

What happens if the registry information is lost in the Year 2000 computer problems?

Will the registry be limited to immunizations?

II. Content of the registries

A. Initial reactions to the type of information typically in a registry

- As in other groups, the first comment was a positive one about the inclusion of the company name and lot number.
- One participant suggested also including where the shot was administered to “pinpoint” where to find people even better than information typically included will.

B. Reactions to including home address and phone number

- Participants had mixed reactions to the inclusion of a home address and phone number. Most participants seemed to agree that this would make it easier to contact people, but someone pointed out that it might be difficult to maintain up-to-date address records.

C. Reactions to including parent or child Social Security number

- Few participants voiced strong opinions about including Social Security numbers. As noted above, one participant voiced an objection to it even before the moderator indicated that Social Security numbers might be included. However, no one else expressed strong concern. One participant said she might be concerned if private companies would have access to the information. Other participants said that they were unconcerned:

I know a lot of people have a problem with people picking up on their Social Security [number]. People do not like the government knowing all this stuff about them, but nothing bad has ever happened to me...

Well, they pretty much have your Social Security number or your daughter's as soon as you apply for one, so I don't know if it would really matter.

D. Reactions to including healthcare members enrollment identification (WIC, Medicaid numbers)

- Participants did not think this would be useful because WIC, and possibly Medicaid, enrollment are both likely to be temporary.

III. Access

A. Who should have access

Participants thought that the following should have access to the information:

- Doctors
- Parents
- Schools, if parents authorize it
- Some people thought schools should not have access either at all or without authorization. There were a few comments such as:

I'd rather have it be my responsibility to call the doctor and let them know they need to send faxes over to the school.

A signed authorization is a good idea: 'You have my written permission to call the registry.'

Don't take it out of the parent's hands. It's a parent's obligation.

B. Who should not have access

- Daycare was the only place cited without probing by the moderator. When the moderator asked about whether it was acceptable for information to be accessed by other registries, health insurers, or public health researchers, most people seemed to

be somewhat concerned about any of these having access. For example, comments included:

I just don't see why anybody would need it.

You're getting very broad and expanding. Nothing the government does ever stays small.

[Insurers] have no right to that information.

The only good thing I could see [about providing the information to researchers] is if they could narrow down why certain people don't have immunizations.

If some researcher wants to get my records, well, they could ask me and tell me why or something. I'd probably give them permission, but I don't want them just rooting around without me knowing about it.

C. Reactions to the idea of linking registry by computer to other health information systems

- As noted above, most participants were uncomfortable with the idea of registry information being accessed by anyone other than parents and doctors.

IV. Consent and inclusion

A. Reactions to “opting out” option

- Most participants said that they would not opt out. However, several people were concerned about how it could be assured that you would be notified if the option was not presented right at birth or at the first immunization appointment.

Comments included:

You've moved and you don't get that notice and if the notice doesn't catch up with you, you don't get the chance to opt out, it's automatically in there...

I think it's a good idea as long as it's done right at that time.

- One person raised a concern about whether you could opt out later if changes were made to the system that were unacceptable to you.
- Participants thought that this option would result in more people being in the registry than other options would.

B. Reactions to “consent” option

- Most participants thought this was the best option – and that they would give permission.

Comments included:

At least this way, they're not going to put you in something that you wouldn't want to be in without your consent.

[I like this best] because, I hate to say it, it's in your control. I have control over whether I join this registry or not.

C. Reactions to “automatic” option

Participants did not like that this provides parents with no option.

Comments included:

They're taking control and I don't like that. I like to have control over what the state should and should not do.

I wouldn't want to take the rights away from someone who wouldn't want to give permission.

SECTION 3: WRAP-UP AND CLOSING

I. Most important benefits of registries

- Convenient way to obtain information that schools require
- Everything is in one place even if you move
- Easy access to information that might be needed in an emergency

II. Greatest concerns/biggest risks

- Discrimination against people who choose not to vaccinate
- Access by unauthorized individuals or organizations

III. Influence of healthcare provider in decision to participate in a registry

- Most people said that their providers' opinions would influence their decision to participate.

Comments included:

I make my own decisions but if [the doctor] said something [negative], it would make me wonder.

I'd probably ask my doctor his opinion of it prior to doing it.

I don't take everything my doctor says to heart, but I do listen to what he has to say.

IV. Suggestions/comments to people who are responsible for how system works

- Participants' closing suggestions and comments included:

Accuracy of information input [is important].

Keep the records straight.

Parental consent is important as an option. (Two participants wrote this.)

Keep everything confidential unless otherwise authorized. (Two participants wrote this.)

First of all, get it going. It sounds like a really good idea and I really think it would be a good idea to have the opt out decision before birth. That's when you're thinking clearly.

Notification of any changes in the program and your 18 year old children taking over their own files [are important].